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The Management of Confidentiality and Anonymity in Social Research

Rose Wiles, Graham Crow, Sue Heath & Vikki Charles

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This article explores the ways in which social researchers manage issues of confidentiality and the contexts in which deliberate and accidental disclosures occur. The data are drawn from a qualitative study of social researchers' practices in relation to informed consent. It comprised 31 individual interviews and six focus groups as well as invited email responses with researchers working with vulnerable groups or with an interest in research ethics. Researchers reported feeling compelled to break confidentiality when participants were perceived as being at risk of harm but not in cases of involvement in illegal activity. Situations in which accidental disclosures occurred were also identified. Researchers reported varying ways in which they protected the confidentiality of their participants in the dissemination of their research, including omitting data and changing key characteristics of participants. The implications of researchers' practices on data integrity and relationships with participants are discussed.

Introduction

The notion of confidentiality is underpinned by the principle of respect for autonomy and is taken to mean that identifiable information about individuals collected during the process of research will not be disclosed without permission (BSA, 2004). The concept of confidentiality is closely connected with anonymity in that anonymity is one way in which confidentiality is operationalised. However, anonymisation of data does not cover all the issues raised by concerns about confidentiality; confidentiality also

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means not disclosing any information gained from an interviewee deliberately or accidentally in ways that might identify an individual. In a research context, confidentiality means (1) not discussing information provided by an individual with others, and (2) presenting findings in ways that ensure individuals cannot be identified (chiefly through anonymisation). This article uses this broad definition of confidentiality to explore the difficulties researchers experience in relation to the issues of confidentiality and the practical ways in which researchers manage these issues. We focus on deliberate and accidental disclosure of confidentiality and the processes researchers use to manage these issues, including anonymisation.

Methods

This article draws on a study focusing on researchers' management of informed consent in social research. It involved collecting qualitative data with academic and professional researchers and focused specifically, but not exclusively, on researchers who conduct qualitative research in the areas of childhood, youth, older people, palliative care, learning disability and mental health.

Thirty-one telephone or face-to-face interviews were conducted with experienced researchers with reputations for work in these areas or in research ethics more broadly. These individuals were identified through our knowledge of the substantive areas, recommendations from other researchers and literature and web searches. Individuals were invited to participate by email with an attached information sheet and consent form. People were invited to return the consent form to indicate willingness to participate. To obtain our sample of 31 participants, we approached 40 researchers. Six focus groups were also conducted in six academic institutions which had recognised expertise in each of the topic areas. To identify our 35 focus group participants, we approached a senior academic in each institution and asked them to identify up to eight people in their institution or locality as potential participants. Potential participants received an email invitation to participate along with the information sheet and consent form. These groups comprised experienced researchers, academics and PhD students. The interviews and focus groups were designed to elicit information from researchers relating to their views and practices around gaining informed consent from people involved in their research. To supplement our data, we emailed 33 experienced researchers working in these areas inviting them to respond by email to specific issues. These individuals were also asked to complete a consent form. Ten of these individuals responded.

We adopted fairly formal consent procedures in this study. The consent form asked participants to respond and consent to 11 questions including agreement for anonymised quotes to be used in study publications and asking whether they wished to review their transcript before agreeing to its use in the study. All study participants agreed to anonymised quotes being used in publications and around a quarter of interview participants asked to review and, in some cases, amend their transcript. These formal procedures were adopted because we were aware that data might be sensitive and that anonymisation might present difficulties. We explore the ethical implications

of the study and our consideration and management of these issues elsewhere (Wiles, Charles, Crow, & Heath, 2006).

The transcripts of the interviews and focus groups were entered into separate datasets using NVivo to allow thematic analysis to be undertaken. Analysis of email material was used to supplement the findings within the specific themes. One of the issues emerging from our study was the management of confidentiality.

Breaking Confidentiality: Deliberate Disclosure

It is recognised that there may be occasions when researchers feel the need to break confidentiality (see BERA, 2004; BSA, 2004). Legal and regulatory frameworks influence how these issues are dealt with (Masson, 2004). In cases of public safety, researchers might be expected to break the confidence of a participant if they disclose having committed or being about to commit a crime (see Gregory, 2003, p. 54). In addition, researchers may feel a moral duty to disclose information if a study participant reports being a victim of crime or if a study participant is perceived as being at risk of harm. This issue is particularly pertinent in relation to child abuse (Bostock, 2002). For practitioner researchers, this issue is difficult as they have a professional responsibility, and in some cases a statutory one, to report situations or individuals they have concerns about to their managers or other professionals; they risk disciplinary action if they do not do so (Allmark, 2002; Masson, 2004).

The literature notes that researchers should think through the circumstances in which they might feel they need to break confidentiality and to alert participants to these as part of the consent process (DVRG, 2004; Ritchie & Lewis, 2003). The expectation is that, should issues emerge during a study the researcher should discuss the need to disclose this and get participants' permission before doing so (Ritchie & Lewis, 2003; Wright, Waters, & Nicholls, 2004). A problem arises for the researcher if the participant does not agree to the issue being disclosed and there is little discussion in the literature on how this should be managed.

Our study indicated that while researchers felt duty bound to break confidentiality where participants were at risk of harm, this did not extend to a perceived duty to disclose information relating to involvement in crime or other illegal activity. The decision to break confidentiality was one that was taken very seriously and was only undertaken where this was seen to be in the best interests of the person involved.

Researchers noted that there were some situations that they were compelled to report (although this may actually be more of a moral obligation than a legal one). Most researchers working with vulnerable groups, such as children and people with learning disability, were unequivocal that they had a legal duty to report abuse but that they would always gain permission from the research participant to do so. Researchers working with vulnerable groups where issues of abuse might emerge reported flagging up these issues prior to data collection. Only one case was identified where a research participant did not agree to disclosure and in this case the researcher arranged support for the person involved but did not report it. Nevertheless, even with participants' consent for disclosure, it was clear that decisions to disclose

information were not made without considerable thought and concern as to the consequences:

Well I think it's a bit of a grey area because the teachers have a duty to report [but] do researchers? I think we may not be covered by the letter of the law but I think in the spirit of the law that we have to report. And I think I would have to say to the child, the promise of confidentiality would have to be framed in terms of the fact that if I find they're in danger, then I would have to speak to somebody but I'd try and do it with them. But by disclosing that kind of stuff you can make it so much worse for the child, I think it's tremendously fraught. (I26, professional researcher, childhood)

For researchers conducting research in the area of illegal activities or where issues might be disclosed relating to criminal activity, the issues are somewhat different. While researchers may be obliged to report a potential or actual crime, such disclosure would mean alienating research participants and, furthermore, that research on illegal activities could not be undertaken. Researchers did not feel compelled to report such information. In some cases researchers reported undertaking active strategies to avoid such information being disclosed to them so that they would not be placed in the position of having to decide whether or not an action needed reporting:

I would find it terribly hard to break confidentiality. I personally would find it terribly hard to go in there and say 'I would respect what you say as confidential but if you tell me.' I mean what we do is, because our study is connected to euthanasia, the minute they start talking about euthanasia ... we stop it right there and get back onto the topic. (FG3, academic researcher, palliative care)

Working in the drugs field, there's certain guidelines you need to follow and you need your participants to be aware of what's confidential and what can't be confidential and what you want to know and what you don't want to know. (FG4, academic researcher, youth)

In some research contexts relating specifically to illegal activity, the fieldwork was conducted on the understanding that the information provided was confidential. However, researchers were aware that they might have to provide information should the authorities become aware that they had it. No cases were reported where this had occurred. Indeed, the research literature indicates there have been no cases where social researchers have been forced to reveal information collected for research purposes in the UK although such cases have been reported in North America (Lee, 1993, p. 164; Van den Hoonard, 2002, p. 8). Nevertheless researchers in our study expressed an awareness that this could happen:

well the criminals we've just interviewed were disclosing crimes that they've done which they hadn't been caught for and I said to them 'this will not go any further than me and the rest of the research team' but if for some reason the police found out I think we would have been on very dodgy ground in terms of perverting the course of justice if we wouldn't give them the information. (FG4, academic researcher, criminology/youth)

Our data indicate that this is an area of great uncertainty for researchers. The research ethics guidelines for researchers reflect this uncertainty. It is interesting to note that while the BSA guidelines (2004, p. 5) state that 'research data do not enjoy legal privilege and may be liable to subpoena by a court', the SRA guidelines (2003,

p. 39) note that, citing Grinyer (2001), 'it is the social researcher's responsibility to ensure that the identities of subjects are protected even when (or perhaps especially when) under pressure from authoritative sources to divulge identities'. Researchers studying illegal activities recognise their research involves them having to balance issues of legality and morality in how they manage their research. Most researchers in the UK working in these areas appear to work in ways that enable them to avoid any legal pressure to divulge information. However, there is an awareness that this situation might not continue indefinitely. Increasing levels of ethical regulation and governance mean that researchers working in these areas may not be able to operate in ways that protect participants, thus rendering some research unfeasible (Adler & Adler, 2002; Wiles et al., 2006).

Breaking Confidentiality: Accidental Disclosure

Letting Something Slip

All ethical guidelines for social researchers are clear that confidentiality is an important element of social research and that research participants should be made aware of who will have access to their data as well as being provided with details about the processes of anonymisation (BSA, 2004, p. 3; Oliver, 2003). There is little discussion about why and how researchers might break this promise of confidentiality other than to protect the participant from harm. Except for poor processes of anonymisation, it appears that breaches of confidentiality are seen as such bad practice that the possibility of their happening does not even need to be addressed.

However, researchers in our study noted that at times they found themselves 'accidentally' breaking confidentiality. These situations included talking to others outside the research team about their research because of a need for support or as a result of inadvertently 'letting something slip'. Discussion of cases within research teams is often written into the research process. Indeed, the research literature notes that this is a good practice and that there should be processes for supporting researchers, agreed by research participants, such as de-briefing among the research team (Corden, Sainsbury, Sloper, & Ward, 2005; Gilbert, 2001). Where these processes are established, confidentiality is clearly not breached by discussions within the research team, although such practices do have implications for team ethics and highlight the importance of all members of the team (including those transcribing data) having an explicit and agreed understanding of confidentiality.

However, not all researchers receive access to the level of support that they may need. Researchers conducting fieldwork that is emotionally challenging are likely to feel the need to 'offload' with someone (Lee-Treweek & Linkogle, 2000). Indeed, it has been noted that this is an important way of managing the emotional risks inherent in conducting research (Corden et al., 2005). Where processes are not in place to enable this to occur in the research team, researchers may discuss the research with others who do not necessarily work to the same understanding of confidentiality. Even when the research has not been emotionally challenging, researchers may feel the need to discuss particular interviews with colleagues or others simply because the issues emerging have been interesting or because they have particular resonance for them. Most researchers recognise the importance of keeping discussions of data within the research team but nevertheless researchers in our study recognised how difficult it was at times to avoid 'letting something slip':

I have to say sometimes [keeping confidentiality] was a tough one because sometimes you've got something really juicy ... and there were times when I, and we've all done it, interviewed some complex and interesting people and been dying to talk about it ... and you can be really careful at first and then two months down the road you can say something and you know that person could be identified ... it can be difficult, you can let something slip. (FG3, academic researcher, palliative care)

It's very hard especially with some of the stuff that we do which is on very, very sensitive issues. I mean you're talking about death and dying on a regular basis and you do need to speak to someone and have all that debriefing so you need to make sure you speak to someone but [that] it's not to someone who can use that information in a wrong way. So you discuss it with your research team or someone who has similar interests and, or within your group. (FG3, academic researcher, palliative care)

Anonymisation

The chief way that researchers seek to protect research participants from the accidental breaking of confidentiality is through the process of anonymisation. Ethical guidelines and methods textbooks all note the importance of anonymising research participants through the use of pseudonyms. There is increasing awareness that research participants, particularly children and young people, may want to be identified and not anonymised in research outputs (BERA, 2004; Grinyer, 2002). In these circumstances, researchers are advised to obtain written consent that an individual wishes to waive their right to confidentiality (BERA, 2004). This indicates that anonymity through the use of pseudonyms is still the norm (Corden & Sainsbury, 2006, p. 22; SRA, 2003).

However, ensuring confidentiality in the presentation of findings, particularly in qualitative research, has been identified as problematic (e.g. Gregory, 2003, p. 53). In most qualitative research confidentiality (through the process of anonymity) cannot be assured; researchers can claim that they will endeavour to ensure that participants are not able to be identified but they cannot promise that this will be the case (Van den Hoonard, 2002, p. 8). Ethical guidelines and methods textbooks contain limited discussion about the ways in which identities can be disguised beyond the use of pseudonyms and the implications anonymisation might have on the data. Methods textbooks and research guidelines note the difficulties in balancing 'disguise and distortion' (Becker & Bryman, 2004, p. 345; BSA, 2004, p. 4; Lee, 1993, p. 187; SRA, 2003, p. 39).

In some cases, researchers may feel it is necessary to avoid publication altogether or to omit certain aspects of their data or individual cases in order to protect people's identities, especially in cases where dramatic or extreme situations are described (Corden & Sainsbury, 2006). The literature notes a number of harms that might arise from people being identified ranging from embarrassment to violence (Lee, 1993, p. 191). Becker notes that decisions about this should be made on the basis of balancing potential

harms to participants with potential benefits of making knowledge public although the difficulties in making such judgements are acknowledged (Becker, 1964).

Most researchers in our study viewed protecting people's identity as challenging, especially in some types of research such as studies of organisations or communities, applied research and evaluations. Issues of anonymity are less problematic in the case of research focusing on general social phenomena in which the identification of the specific context from which participants are drawn is unnecessary. Nevertheless the majority of researchers in our study still took the issue of anonymisation very seriously.

Researchers demonstrated different orientations to the anonymisation of participants. Some researchers viewed the responsibility for protecting the identity of participants to be theirs because they had the knowledge to assess the risks to participants. Other researchers viewed the responsibility to lie with participants; they felt it was for participants to decide what data that they had provided should be included and how they were anonymised (or identified) in relation to these. These two orientations are not discrete categories; they can more usefully be seen as extremes on a continuum with researchers located at different points according to their research approach, the context of their research and the specific issues they faced.

Researchers whose orientation was towards them being primarily responsible for decisions about confidentiality reported giving careful consideration about whether to use data obtained from a particular individual if it might mean that person could be identified or if identification might have undesirable consequences for an individual or an organisation. Several researchers noted that people's stories can be very individual and that simple anonymisation, or even changing key characteristics, is not sufficient to avoid their identity being discovered. There was a sense that deciding not to use data at all because of these risks was a difficult decision to take because it meant that some of the most important data and the issues contained therein had to be omitted. Nonetheless, in these cases, researchers viewed the protection of the participants' identities to take precedence over the need to publish the data:

I think you have to be terribly careful how you write things up to conceal people's identities and disguise them ... some of the worst things I've seen I've never written up and I feel I've betrayed the people it's being done to but I think: well, I don't think I'm going to gain anything by writing it up. (I2, academic researcher, childhood)

It's part of your responsibility as a researcher to watch out for things that might be dangerous for the person who's talking to you so that you are able to make your own careful and ethical judgements about whether something should be used because sometimes people given consent and really they shouldn't have. (I26, professional researcher, childhood/youth)

The desire to use data in cases where distinctive stories might make individuals identifiable led some researchers to change the identity of participants in various ways. Several researchers noted that they had become skilled at disguising individuals by changing their key characteristics. Researchers adopting this practice noted that this could be done only if it did not affect the integrity of the data:

Some of the people I've interviewed have got very distinctive stories and you have to develop ways of ensuring their anonymity. ... Sometimes when there's an issue that I want to get on the printed page but I need to preserve their anonymity then I might turn a him into a her or change the age or the part of the country. ... You'd only do that if it doesn't make any difference to the message you're giving, and sometimes it does and sometimes it doesn't. ... You can separate out, I had one person, a lot of whose story was very relevant and telling and I actually split it into two different people. (II, professional researcher, childhood)

Some of the issues with the children we interviewed, we had to go through all sorts of contortions which ultimately we weren't always happy with, like for example, we felt we'd better change the gender of this child, we'd better change the age and you start to think: is this an ethical thing to do? But you actually felt that the imperatives of the moment were such that you would do that rather than the child be identified. (FG5, academic researcher, childhood)

Researchers who oriented themselves as having primary responsibility for protecting participants did not check back with participants to see if they were happy with how their identities had been changed. They viewed themselves as having appropriate knowledge about what would best protect participants:

I haven't gone back and said 'here it is, here's what we've done, do you want to change anything?' because I suppose I think at that stage I take responsibility for what goes in, as long as I'm protecting them. I take responsibility, I shouldn't put that on the people taking part in the research. (I21, academic researcher, family)

Specific types of research were identified as raising additional difficulties in relation to confidentiality. Research involving data collection from couples or families in which the accounts about others, or attitudes towards them, differ present particular problems of confidentiality and anonymisation. Researchers noted the importance of careful anonymisation and decision-making about how data were used so that family members would not be able to recognise the views of kin where these were not in accord with their own. Researchers also noted the difficulties inherent in research where other people were discussed, especially where these involved negative comments or accusations against other people who might be able to identify themselves, be identified by others or identify the participant. Again a careful consideration of anonymisation in the presentation of data was identified as important and, in the cases cited, it was researchers who made the decisions about how these should be managed:

There are really difficult issues when you are interviewing members of a family or couples, or people who are in a relationship and you are putting their accounts side by side. There are some very difficult issues there and we often try to side-step them by changing enough so that we're hoping that the person they're talking about won't be able to recognise themselves if they read it. It's very common for people to tell you things that you think would be hugely problematic if their relatives knew they'd said that ... I think it's important to exercise judgement about the impact that that could have in the network that the person comes from. (I21, academic researcher, family)

There has been an increasing debate questioning the assumption that study participants want anonymity and the difficulties involved in engaging with this (Corden & Sainsbury, 2006, p. 22; Grinyer, 2002). This issue was raised by several researchers who noted that participants, especially children, young people and the bereaved,

increasingly expect their own names and/or those of their deceased relatives to be used. Many of the researchers who were oriented to taking responsibility for protecting participants noted that, in such circumstances, they would not agree to the participant's real name being used. In some cases this was because they viewed anonymisation as a core principle of ethical research practice that could not be breached. For others, it related to the difficulties inherent in breaching confidentiality for some individuals and not others:

I've been in a situation where young lesbians and gavs have said to me 'no. I want you to use my real name', you know, 'I am completely out, I don't care who knows it's me.' And in that situation I would, I've always said to them 'well that's up to you who you choose to be out to, but I can't do that.' (I26, professional researcher, childhood/youth)

One of the intensive care units was bitterly disappointed that her unit wasn't named, but I had to explain that if I identified the unit then there would be a cascade of identification, you know, and people would be able to potentially identify all the staff and all the patients. (FG1, academic researcher, palliative care)

Other researchers' orientation to confidentiality and anonymity was that research participants needed to be involved with this process. They viewed it as important to work closely with research participants in making decisions about how these issues were managed. These researchers tended to adopt participatory approaches to their research, to varying degrees. These were mostly researchers conducting research with children and young people or in palliative care. Several researchers with this orientation noted the importance of 'checking back' with research participants how the data they had provided would be used. These researchers were willing to withdraw specific data if participants were unhappy about its inclusion:

You can never guarantee how people will read the reports so you need to get people to clear their comments even if you do anonymise them because, you know, people will make guesses and people won't read it as fairly as you have written it. (I18, academic researcher, education)

In relation to the use of pseudonyms, researchers with this orientation noted the tendency for some research participants to want their own names to be used and the importance of enabling this to happen. The assumption that anonymity is desirable was very much questioned by these researchers:

I think increasingly there are several areas where people are beginning to say 'no, anonymisation's not the ethical thing to do'. (I18, academic researcher, education)

My view is about negotiating with individuals and not making assumptions about what they may or may not want ... I think the assumption that anonymity is always wanted by people needs to be challenged. (FG1, academic researcher, palliative care)

Discussion

In this article we have reviewed the range of issues that concerns about confidentiality raise and the ways in which researchers deal with them. A number of issues emerge from this.

First, our research indicates that it is common practice for researchers to change the characteristics of study participants in order to protect their identities. It is noted in ethical guidelines and research methods literature that the practice of changing characteristics in order to disguise participants should not occur if this distorts the data (BSA, 2004). However, evaluating the impact of such changes is difficult. One of the difficulties with the practice of changing participants' characteristics is that the readers of the research often do not know that such changes have been made at all or, if they do, do not know precisely what these changes encompass. This means the reader cannot judge the extent to which these impact on the integrity of the data. This has significant implications for the transparency of research and for assessments of rigour.

A related issue concerns the extent to which participants' views should be taken into account in making these changes and the ethical issues that arise from this. Corden and Sainsbury (2005, p. 18) found that people had strong views about the use of pseudonyms which was felt not only to be risky but also dishonest. We do not know research participants' views about having their characteristics changed in research reports but this is an important topic for further exploration. There is some indication that research participants increasingly want to be identified; some researchers working in specific substantive areas, such as in childhood and in palliative care, adopt approaches that encourage them to work closely with individuals in making decisions about this issue. In the context of developing technologies and innovative practices in social research and its dissemination, such as the use of visual and online methods, it may be time to re-think what anonymity means in twenty-first century social research. In a culture of increasing individualisation where people want to have their story told (Silverman, 1997; Wiles et al., 2006), it may be that the notion of anonymity is one that is appropriate, or desired, only in particular types of social research.

Second, our study identified the issue of accidental disclosure by researchers resulting from a need for support or simply as a result of 'letting something slip'. This issue is one that appears to be frowned on by the research community, and largely ignored in the methods literature, yet this is the reality of research for many people. The need to support researchers, especially junior researchers and those working on sensitive issues, through de-briefing and/or the availability of counselling support is clearly an important issue. The issue of 'letting something slip' is more problematic. Complete confidentiality in research is impossible because the purpose of gathering data is to obtain new knowledge, to synthesise this knowledge and to disseminate it. There are many reasons why researchers might discuss the data they have generated such as: to develop their thinking; to disseminate their findings; to assist another researcher working on a similar topic or for teaching purposes. Researchers cannot know the extent to which it might be possible for the people to whom they are talking to identify an individual by what they say and thereby the contexts in which confidentiality is breached. Perhaps it is time that we think through more clearly what confidentiality in research actually means in practice and what research participants understand and expect from researchers' promises of confidentiality. Such issues are only just beginning to be addressed (see Corden & Sainsbury, 2005; Graham, Grewal, & Lewis, 2006) and are worthy of further consideration.

Third, our study indicated that the intentional breaking of confidentiality because of concerns about participants' safety is an issue that raises a number of concerns for researchers. Researchers appear to feel a responsibility to report, with their participants' permission, cases where their participants are at risk of harm but not cases of illegal activity. There is a clear consensus that the abuse of vulnerable people should always be reported with participants' permission. What is not clear is what actions researchers might take in cases where participants refuse permission. We also do not know what impact disclosure has on the participant over the longer term. There appears some confusion around legal responsibilities regarding disclosure about both risks of harm and illegal activities. In an increasingly regulated research environment, there is some concern researchers may not continue to be able to make their own decisions about these matters and, indeed, that some research might become unfeasible. In the context of increased institutional ethical regulation and governance and increased fears about litigation, the expectations that employing institutions and gatekeepers have of researchers are important issues that need exploring. This applies also to the ways these expectations are communicated to researchers and the outcomes for researchers flouting these expectations.

Conclusion

Social research in the UK is witnessing increasing ethical regulation and concern with litigation but simultaneously a trend towards greater consumer involvement in research. This can be seen as a conflict between paternalism on the part of researchers and their employing organisations and autonomy on the part of research participants. Researchers face a dilemma: on one hand they want to protect their participants and many feel that it is they who are in the best position to do so, but on the other hand, many want to work participatively and provide choice to research participants about the ways in which their data are used. Rather than increasing regulation to determine the ways in which researchers manage these issues, employers need to ensure that researchers have access to adequate training and support so that they have the ethical literacy that enables them to make appropriate ethical decisions that operate in the best interests of research participants within the context of a specific study.

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